COMMUNITY HEALTH WORKERS AND HOME-BASED CARE PROGRAMS FOR HIV CLIENTS

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In Nyanza Province, Kenya, estimated HIV prevalence is 22%. Given that more than 80% of the population resides in rural areas, the majority of individuals in Nyanza Province do not have access to medical facilities on a regular basis. In response to the growing demands the HIV epidemic has placed on the people and communities in this region, hundreds of lay individuals have been trained as community health workers to provide home-based care to sick or dying HIV/AIDS clients in rural areas. This paper discusses the role and impact of these community health workers in Nyanza Province, Kenya. It outlines the collaborative relationship between community health workers and the Ministry of Health, examining community health workers' use of extant biomedical structures at the district level to provide services that government-run health facilities lack the monetary resources or personnel to provide. Finally, it explores the role played by community health workers in providing HIV/AIDS education to individuals in an attempt to prevent further infections. (*J Natl Med Assoc.* 2004;96:496–502.)

Key words: HIV/AIDS ◆ rural health ◆ community health workers ◆ home-based care

INTRODUCTION

Between 1985 and 2002, over two million Kenyans became infected with the HIV virus.[1] As the majority of those infected were young adults, this epidemic had a tremendous impact on multiple sectors of Kenyan society—leaving over one million AIDS orphans and further devastating an already damaged economy. In response to former Kenyan President Daniel arap Moi's declaration that AIDS is a national disaster,[2] numerous organizations were established throughout the country to reach out to those infected and affected by this disease, as well as to aim to reduce its prevalence in the future. This paper will specifically examine the role played by community health workers (CHWs) in providing home-based care to individuals infected with HIV/AIDS and HIV/AIDS education in rural communities in Nyanza Province, Kenya. It will also discuss how community-based care programs are working collaboratively with existing biomedical bodies to provide services that such infrastructures do not have the resources to provide.

Literature Review

The vast majority of research and commentary on the HIV/AIDS epidemic in Kenya contends that cultural and socioeconomic factors are the main causes of the high prevalence of this virus. Traditionally, the male is the sole breadwinner in the family and, depending on his economic status, may have two or more wives.[3] Upon the death of the husband, his wife or wives are inherited by his brothers or other close relatives in order for the woman to be guaranteed continued financial support for herself and for her children. Before the rit-

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ual of wife inheritance is complete, each wife must undergo a cleansing ritual in which she is required to have sex with a stranger.[4] If either the widow or the wife cleanser is infected with HIV/AIDS, his or her sexual partner may become infected with the virus, and the disease is then spread throughout the woman's new compound or to the wife cleanser's other sexual partners.

Internationally, CHWs have played a vital role in providing education and treatment for a variety of diseases and public health issues at the grassroots level. According to the literature, "community health workers are typically members of a particular community whose task is to assist in improving the health of that community in cooperation with the healthcare system or public health agencies."[5] In the United States, CHWs have worked with minority populations on a variety of issues ranging from breast cancer screening for Native Americans,[6] to diabetes education in latino populations,[7] to breast and cervical cancer screening among low-income minority women.[8] In other nations, the work of CHWs has included assisting with care of tuberculosis victims,[9] providing healthcare to rural villages in Nepal,[10] and providing health education to women in Iranian communities.[11]

The role of CHWs in providing care and prevention education to their communities in response to the HIV/AIDS epidemic was found to be successful in Kenya's neighboring country, Uganda—the only sub-Saharan African nation where HIV/AIDS prevalence has shown a significant decline. In Uganda, the target audience of the behavior change campaign has included both at-risk populations and the general population. Thousands of individuals were trained as community-based AIDS counselors, health educators, and peer educators to disseminate prevention education. As Green et al. note:

"Led by their leaders' examples, the general population in both urban and rural areas eagerly joined the fight against AIDS, so that it became a "patriotic duty" to support the effort. Spreading the word involved not just 'information and education' but rather a fundamental behavior change-based approach to communicating and motivating.

"Decentralization itself was actually a type of local empowerment that involved a local allocation of resources—in itself a motivating force."[12]

An enormous amount of the nongovernmental action for HIV/AIDS services in Uganda has been carried out by religious leaders and faith-based organizations in response to the HIV/AIDS epidemic. The involvement from both Christian and Islamic religious communities has included both prevention education programs and support for the infected and affected; these programs have been among the most respected and well-received programs among the Ugandan people. For example, a program created by the Islamic Medical Association of Uganda (IMAU) to train religious leaders and lay community members as educators and CHWs has been selected by UNAIDS as a "Best Practice Case Study."[12]

Methodology

This study was conducted in four different districts of Nyanza Province in western Kenya between July and September of 2002. The communities represented include an urban environment in Kisumu, a small town in Rachuonyo District, and rural communities in Nyando District and Nyatike Division of Migori District. The majority of individuals living in these districts are members of the Luo ethnic group.

The data for this research were gathered using qualitative and ethnographic methods. The dominant method utilized in this study was participant observation and included observing the Ministry of Health and community-based organizations' daily activities, attending Ministry of Health-sponsored meetings, visiting area health facilities and HIV/AIDS clients in their homes as part of home-based care programs, and attending a portion of a training session for CHWs in Nyando District. Data collection also included approximately 30 informal unstructured interviews with organizational leaders, organizational members, Ministry of Health employees, and community members; and 16 semistructured open-ended interviews with governmental leaders, organizational leaders, and CHWs divided among the participating organizations. In addition, a focus group discussion was held in Nyatike Division with nine youth. All informal interviews were written in a field notebook and all semistructured interviews and the focus group discussion were tape-recorded with the permission of all participants and later transcribed. In cases where informants did not speak fluent English, a translator was used during the interviews and the focus group discussion. These translations were later verified through the use of a bilingual English-Dholuo dictionary. To capture the knowledge, attitudes, and practices of a broad range of members of each community, Ministry of Health

personnel, local government officials, organizational leaders, HIV-positive organization members, and community members at large were interviewed for this study. It should also be noted that this research was approved by Oregon State University's Institutional Review Board and special permission was granted to use participants who were age 15 and above.

A Glance at Four Home-Based Care Programs

The home-based care program itself is a nationwide program that consists of a process of eight components: community mobilization, community support through sustainable income-generating activities, training of CHWs, client identification, training of primary caregivers, implementation, monitoring, and evaluation.[13] The data presented here primarily reflect home-based care programs offered by four different community-based organizations in Nyanza Province —Miwani Home-Based Care in Nyando District, Oyugis Integrated Project in Rachuonyo District, Nyatike Home-Based Care in Migori District, and Omega Foundation in Nyando District.

CHWs are usually lay people from the community who participate in a one- or two-week training program. A number of the CHWs recruited for the HIV/AIDS Home-Based Care program have previously been CHWs with other organizations, such as Association for the Formation and Support of Development (AFAD) and CARE Kenya—organizations that work with environmental sanitation, educate communities about proper sanitation, and help to prevent and treat diseases (such as measles, cholera, and eye infections). In home-based care training sessions, the CHWs learn a variety of information about HIV/AIDS, methods of prevention, and care and management of the sick and dying. The objectives of these training programs include: "1) to empower CHWs with skills on home-based care to reduce stigmatization of people living with HIV/AIDS within the community; 2) to ensure that the CHW worker is equipped with skills to care openly and compassionately for HIV/AIDS infected people; and 3) to equip participants with skills to be able to identify people who are positive and to be able to train them as care-givers and in personal hygiene."[14]

Miwani Home-Based Care

Miwani Home-Based Care is a community-based organization working in three sub-locations in Nyando District—Nyangoma, Northeast Kano, and Ombeyi. The total population of the region served is 58,029. Although the number of HIV-positive individuals in these locations is unknown, estimated HIV prevalence for Nyando District is 28%.

The target population of this organization is people living with HIV/AIDS and AIDS orphans. The program initially started in the year 2000 and is partially funded by the HIV/AIDS Prevention and Care Program (Hapac), a program subsidized by Future Group of Europe and centered in Nyanza Province that provides temporary grants to HIV/AIDS-related community-based organizations; Hapac funding for Miwani Home-Based Care ended in March, 2003. Aside from this outside aid, the program is operated on community-generated microfinance projects, including plowing, selling *posho* (maize meal), and small-business enterprises operated by the CHWs themselves. At the time this study was conducted, Miwani Home-Based Care had a total of 172 CHWs.

Although unpaid and given very little tangible incentives, the majority of CHWs interviewed expressed their satisfaction with the work they were doing and noted their desire to become a CHW was rooted deeply in altruism. The spirit of *harambee* (Kenya's national motto—a symbol of national unity which calls all Kenyans together in an altruistic spirit) was a driving factor, and as one CHW from Miwani Home-Based Care explained, he liked to "help people voluntarily so the deadly disease would not finish them." Despite this, the majority of CHWs themselves live in poverty and cited lack of transportation for clients living great distances away from them and lack of tangible incentives as the biggest obstacles in providing home-based care. CHWs typically receive free meals at training sessions and tokens (such as free t-shirts), but as their CHW work takes up a significant portion of their time, they desire to receive incentives—such as monetary stipends, food, and bicycles—to make transportation easier.[15]

Oyugis Integrated Project

In the mid-1990s, Catholic brothers from Kenya and the Netherlands operated a formation house in Oyugis that provided treatment and dressing of wounds. Over time, they noticed that an increasing number of individuals in their community were becoming sick and dying and could not afford to go to the hospital. After realizing that the people were dying because of HIV/AIDS, the brothers performed a needs assessment by conducting a survey

of the community. They visited the homes of community members with the objectives of getting to know the culture better and coming to a better understanding of the problems that the people faced. In 1996, with financial assistance from the Catholic Church in the Netherlands, Oyugis Integrated Project (OIP) was formed with the intentions of working with people who are living with HIV/AIDS and assisting AIDS orphans. In July, 2002, OIP sponsored the training of over 50 new CHWs. Home-based care activities are also conducted by nurses affiliated with the OIP dispensary and members of Youth Fighting AIDS in Kenya theatre group (a group of young adults affiliated with OIP who provide HIV/AIDS education to adolescents through theatrical performances).

During a home-based care visit, the CHW may visit with clients, assist in preparing meals, assist with household chores, give medications to treat opportunistic infections, or conduct a needs assessment to consider what supplies may be needed on the next visit. The CHW is also responsible for training the client's primary care-giver in safe and hygienic care-giving, opportunistic infection recognition, and appropriate medication administration. The primary care-giver is generally a member of the client's immediate family; in the majority of households visited during this research, the primary care-giver was a son or daughter of the client. As the typical CHW visits a client an average of one time per week, the primary care-giver is responsible for responding to the daily needs of the client, and most have not received training in HIV/AIDS client care or HIV/AIDS prevention. The CHWs visit the clients more often when a client urgently needs a medication and less often when the case load is too immense or transportation is difficult. Especially during the rainy season, when roads become muddy and difficult to navigate, the CHWs found it difficult to reach clients' homesteads in rural areas.

Nyatike Home-Based Care

In 1999, the Catholic Diocese of Homa Bay conducted a community-needs assessment in Nyatike Division. When conducting this needs assessment, the Diocese discovered that many people in this community were sick and dying, could not afford treatment, and that the HIV/AIDS prevalence was high. As a result of this research, the Catholic Diocese of Homa Bay created Nyatike Home-Based Care within the same year. The initial objective of this organization, as the name suggests, was to provide home-based care to those people who were suffering from HIV/AIDS and who were in the end stages of their lives. However, a recent needs assessment led to the realization that orphan care and support is another major problem in Nyatike Division. In response to this discovery, Nyatike Home-Based Care has recently decided to provide assistance, such as food, medical care, and educational expenses, to orphans as another component of their activities during their next funding period.

Unlike Oyugis Integrated Project, Nyatike Home-Based Care currently caters to over 500 HIV/AIDS clients. As part of the goals set when the organization was first established, Nyatike Home-Based Care would like to assist at least 1,000 clients in a four-year period; as of August, 2002, they had provided care to 683 clients, which suggests the organization will reach their goal (unfortunately, during this time, over 200 clients have died).

One of the primary roles of CHWs affiliated with Nyatike Home-Based Care is to provide HIV/AIDS education to their communities. In large part, their educational efforts have helped to shape a positive perception towards HIV-positive individuals. However, educating certain groups of people, particularly older men, still continues to be an obstacle for these CHWs. Additionally, the assistance that Nyatike Home-Based Care provides is geared toward providing material support, rather than focusing on psychosocial support, such as is the case with OIP.

As of August, 2002, Nyatike Home-Based Care had trained a total of 60 CHWs. To become a CHW, an individual must be nominated by the community—a process which takes place at the chief's weekly meetings, known as *barazas*. The nominated individuals then receive a letter from the chief's office inviting them to become a CHW and attend a one-week training program.

CHWs interviewed found their educational efforts in the community to be largely successful "because the community members are able to accept the teaching, and they become flexible and willing to be taught." The CHWs also counsel widows on the ramifications of wife inheritance (a traditional custom among the Luo and argued to be a contributing factor in the rapid transmission of the HIV virus in Nyanza Province). As one CHW suggested, the widows are listening. To illustrate his point, this CHW stated, "when I go to a home and

find a widow, and I discuss issues about HIV and AIDS, these women become careful not to be inherited. They prefer to have the [HIV] test done before being inherited."

As most CHWs are themselves volunteers, many desire to receive some compensation for the work they do. In Nyatike Division, the trainers of CHWs have each received a bicycle as an incentive. One CHW suggested that it would be beneficial for all CHWs to receive a bicycle, as "they may be able to visit the clients in their homes more easily." This bicycle incentive would help extend the home-based care service to more individuals.

Omega Foundation

In large part, the Government of Kenya, nongovernmental organizations (NGOs), and community-based organizations (CBOs) rely on one another and collaborate in their attempts to help individuals infected and affected by HIV/AIDS as well as in prevention programs. Because the Ministry of Health has a limited budget, they rely on the NGOs and CBOs to carry out programs that they could otherwise not afford to support.

One CBO working in Nyando District is Omega Foundation. At the time of this study, Omega Foundation was sponsoring the training of approximately 40 CHWs. This organization had hired personnel from the Ministry of Health to conduct the training program because of their expertise in medical treatment programs and HIV/AIDS issues. At the same time, the Ministry of Health was relying on these CHWs, who were affiliated with the CBO, to provide home-based care services to the dying in rural communities where individuals did not have access to health facilities.

Omega Foundation was started in Nyando District in 2002 with the intention of expanding to Kisumu, Siaya, and Rachuonyo Districts in the future. At the time of this study, the organization was primarily funded by income-generating activities, which included *posho* grain grinding, pig rearing, tailoring, farming, and agriculture. Another income-generating activity that the CHWs themselves engaged in was selling essential drug kits for a nominal fee to home-based care clients. Of the money raised from the sale of these kits, 25% of the profit went to the CHW in the form of a monetary stipend, 25% went back to the patients in the form of material support, and 50% went to Omega Foundation to assist in operational maintenance of their programs.

DISCUSSION

All HIV/AIDS clients interviewed for this study agreed that the home-based care program has had a positive impact on their quality of life. As one member of Oyugis Integrated Project explained, "by joining the group you are not alone. I know I'm not alone now. So I am encouraged—as a group, with the help we are getting, the education." Another client of Nyatike Home-Based Care stated that "even though people are tested and they are positive, they are still able to live...We are grateful because when we become sick, our bodies are treated." HIV/AIDS clients also expressed satisfaction with the home-based care program's aims to encourage them not to practice wife inheritance, assistance in providing food, and for the "good company" that the CHWs provide during their weekly visits.

Among the obstacles that organizations face in mobilization efforts for HIV/AIDS education and outreach, the most common response cited by all interviewees was limited funding. To varying degrees, each organization relied on funding from foreign sources for the implementation of their programs. For example, Nyatike Home-Based Care is funded by the Catholic Diocese of Homa Bay, which is funded by a grant from the Archdiocese of Maryland in the United States. The initial funding period is four years and has been designed to provide training of CHWs, HIV/AIDS educational materials, home-based care services, medication, counselors, and rapid testing kits. However, the organization could not afford to provide care and support for orphaned children, due to limited financial resources.

Although the specifics of their programs differed, organizations participating in this research share the common objective of serving the needs of HIV/AIDS clients in their communities and exhibit many of the same plans for the future. All of the organizations place the needs of the infected and affected as their first priority and address prevention of further infections as a secondary priority. Given that the primary tribe in each location was the Luo, each organization is facing many of the same cultural beliefs and traditions that are often times linked to the spread of HIV/AIDS.

The demographic background of the CHWs varied from organization to organization and included mostly women above 30 years of age (Miwani Home-Based Care and Omega Foundation), youth and nurses (Oyugis Integrated Project), HIV-positive individuals (Nyatike Home-Based Care), and tribal

elders from the Office of the Chief (Nyatike Home-Based Care). The findings suggest that recruitment of a broad range of community members is advantageous in reaching the widest spectrum of age and gender in educational endeavors. Additionally, offering training seminars in the CHWs' native language—in this case Dholuo instead of in Kiswahili or English—would increase the number of individuals eligible to become a CHW.

The role of CHWs continues to grow as their responsibilities extend beyond care of the infected and affected and prevention education in the communities studied. An employee of Nyatike Home-Based Care noted that the number of people receiving an HIV test had increased since the program had been implemented and maintained that this was the reason why they had been successful in enrolling people into the home-based care program. According to this individual, as a result of voluntary counseling and testing (VCT) services in this community, "people have come out openly. They are now asking and demanding for the services because the mobilization has been well done. So the community's been very, very responsive to issues around HIV and AIDS."

Access to VCT services and community support services for those who test positive have shaped individuals' willingness to receive a test. According to one CHW affiliated with Nyatike Home-Based Care, "now we are encouraging everybody to go for testing so that they know their status even if they are well." The number of openly HIV-positive clients in this program is indicative of the successes of the VCT program. Another CHW stressed the importance that *anybody* could be HIV-positive and that one of their roles as a CHW was to prove that point. She stated, "people normally want to know if the CHWs have been tested because when they provide counseling services, the assumption is that they have also been tested. I am an example to the community because I have already gone through counseling and been tested."

Additionally, CHWs in Nyatike Division believe that the education they provide to the communities has helped to create a more-positive perception of people living with AIDS. As one CHW explained, "at first, people were afraid of the disease and those who were infected, but through education, through information and communication, through the program, then people have tried to know what it is and to see HIV and AIDS just as one of the diseases."

CONCLUSION

In this paper, we have demonstrated how four community-based organizations in Nyanza Province, Kenya, have mobilized their communities to support individuals infected with HIV/AIDS through training CHWs in rural areas to provide home-based care service to HIV/AIDS clients. The research presented here illustrates the grassroots approach to community organization that these four organizations in three different governmental districts have taken to provide HIV/AIDS education and outreach services. As 80% of the population of Kenya inhabit rural areas, and as most of these individuals have difficulty in acquiring transportation to other areas within the country, this grassroots approach to fighting the HIV/AIDS epidemic is an effective way of reaching members of the communities they serve. But as community-based organizations are struggling for funding in most communities, thus limiting the services they provide, it is important that community-based organizations working with large client bases, such as Oyugis Integrated Project and Nyatike Home-Based Care, work with newly formed and struggling organizations to design effective intervention strategies.

This paper has sought to create a broader framework for evaluating the successes and obstacles of such community-based organizational programs and strategies in the future. Currently, programs assisting the infected and affected may be measured by the number of clients served and the level of services provided to them, but ultimately, the success of prevention programs will be measured by the prevalence of HIV/AIDS in future years. In the face of rising death tolls from HIV/AIDS infection in Kenya, particularly in Nyanza Province, it is essential that action be taken to overcome the issues associated with this epidemic.

Given rural patterns of habitation in Nyanza Province, Kenya and the limited budget and personnel of Ministry of Health treatment centers, CHWs have become an essential component of the health infrastructure to provide care to HIV-positive individuals who cannot easily access biomedical facilities due to distance, financial constraints, and a weakened state of personal health. In addition to their role of providing home-based care to HIV/AIDS clients in rural communities, CHWs also are responsible for providing HIV/AIDS prevention education to their communities. But as the vast majority of CHWs are volunteers who are also living in extreme poverty, it is essential that contin-

uous financial support from outside donors be directed towards tangible incentive programs for CHWs and expanding home-based care services to more clients and communities. An expansion of such services would ultimately provide essential care to an increasing number of individuals suffering from AIDS-related opportunistic infections.

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